Health services research: is there anything to learn from mental health?

Mental health care

The recent history of mental health services can be seen in terms of three periods: the rise of the asylum; the decline of the asylum; and balancing community and hospital care. While the first two periods have been well documented, the third is still underway in most high income countries. In this stage the main goal is to develop a balance of care offering treatment and care with the following characteristics:

- services which are close to home
- interventions related to disabilities as well as symptoms
- treatment and care specific to the diagnosis and needs of each individual
- services consistent with international conventions on human rights
- services which reflect the priorities of service users themselves
- services which are coordinated between mental health professions and agencies
- mobile rather than static services, including those which can offer home treatment.

In terms of the wider context of the global burden of disease, the full impact of mental disorders has only recently been recognised, with the development of two standard metrics (Years Lived with Disability and Quality Adjusted Life Years) that allow physical and mental disorders to be directly compared. The use of the common measures has revealed that eight of the top 20 causes of Years Lived with Disability are mental health problems.1

Limitations of research on mental health services

While many, perhaps most, of the challenges faced by mental health studies are shared by research in other areas of health care, there are additional difficulties: until recently, the use of non-standardised outcome measures was more common; many mental health treatments can be considered complex treatment interventions; and patients lack, or may lack, the capacity to consent.

In relation to randomised controlled trials (RCTs), a serious shortcoming of many mental health trials is that they are not of sufficient statistical power to clearly answer the question posed.2 Compared with many studies in the fields of communicable diseases, cancer and cardiovascular medicine, where trials may frequently include thousands or tens of thousands of patients, to date it is uncommon to see mental health trials including more than a few hundred patients. Further, other fields of health services research often use simple dichotomous outcomes, for example, death or survival over a fixed follow-up period, which can reliably be established from administrative sources, so that completeness rates at follow up can be expected to be very high. By comparison, simple outcome measures are inappropriate for most psychiatric conditions and much more often interval or ratio scales are used to rate outcome.

Although mental health trials started only a few years after the ground-breaking study of streptomycin in 1948, more recently other areas of health care have made much greater use of RCTs. For example, currently there are 2461 trials registered for the treatment of cancer compared with 457 for mental disorders.3 Mental health RCTs may therefore be fairly described as in their adolescent years but with clear promise for early maturation. Balanced against these shortcomings, there are aspects of mental health services research that are pioneering.

Service user participatory research

There has been a rapid recent growth in the involvement of service users in the conduct of research and in the debate over what constitutes evidence.4 It has been estimated that the user movement in the UK, for example, has grown from some 15 groups in the mid-1980s to over 700 today.5 The desire of many of these groups is full participation throughout the research process. One example of such research is the Review of Consumers’ Perspectives on Electro-Convulsive Therapy (ECT).6 This review relied upon existing materials and used 26 papers written by clinical academics and nine authored by consumers or written in collaboration with consumers. In addition, 139 ‘testimonies’ or first-hand accounts of receiving ECT were gathered and most of these were in electronic form, for example, from the Internet. The scientific papers reported much higher levels of satisfaction with ECT than did either the user-led research or the personal testimonies reviewed. Whilst the consumer-led review would traditionally have been criticised for biased sampling, the authors put forward different and user-focused reasons for their results.

Another example of service user participation is a recently completed exploratory randomised controlled trial of Joint Crisis Plans, a form of crisis card, or advanced directive, which were developed with people diagnosed as having a psychotic disorder, when well, to set out clear contingencies in case of a future relapse.7 The trial found subsequently that the degree of objective coercion applied to those with plans was significantly less than to the control group who simply received a package of information about local services.
Perspectives of carers

Compared with information from service users and their advocates, there is little published on the views of family members and other informal carers, either on the type of evidence they value or on the content of research they favour. Where studies have been made of the issues most salient to carers, several recurrent themes have emerged: a sense of loss of expected future of the affected relative; concerns for their own mental health in terms especially of anxiety and depression; financial worries; the need for respite breaks; a clear requirement for information and advice on the psychiatric condition; its cause, future treatment and care options; and fear for the future when they can no longer provide care.8

Because of this expressed need for more widely available information for carers, a website now provides evidence especially for carers of people with mental disorders at www.mentalhealthcare.org.uk.

Evidence-based stigma reduction

Although people with mental health problems frequently suffer both the consequences of their primary conditions and the secondary limitations of discrimination applied to them because of their diagnoses, research on stigma reduction is relatively recent. The World Psychiatric Association ‘Open the Doors’ Global Programme Fighting Stigma and Discrimination because of Schizophrenia is operating in over 20 countries (www.openthedoo rs.com), and is a collaborative framework within which to test candidate stigma reduction interventions. As in the wider field of health care, such evidence is as yet rare, but early findings suggest that knowledge and attitudes, if not behaviour, can be favourably influenced by educational sessions, where the most potent ingredient may be the testimonies of services users.9

Research from multiple perspectives

A further approach to multi-perspective research, within the empirical tradition, is to rate separately the views of staff and service users and to make explicit comparisons, for example on how far needs are met or unmet. In one study in London, for example, a representative group of 137 service users with a functional psychotic disorder was assessed by users themselves and by staff, using the Camberwell Assessment of Need.10 Staff rated service users as having on average 6.1 needs, while users rated themselves as having an average of 6.7 needs, with staff ratings of 1.2 unmet needs, compared with users rating of 1.8 unmet needs. Intriguingly, the most powerful predictor of quality of life was service user-rated unmet needs.

Conclusion

What emerges is not so much that different stakeholder groups take differing views on which evidence is stronger in indicating service priorities, but rather that the epistemological status of evidence is now the subject of debate. Service user-led or user-controlled studies are more often within the qualitative scientific tradition and practitioner-led research more often quantitative. How can any tensions and contradictions be managed if not resolved? We propose that work continues to build what can be referred to as a ‘multiple perspectives paradigm’ to integrate such varied sources of evidence. Meanwhile, we propose increasing service users’ participation in setting research questions, developing a wider range of assessed interventions, consolidating structures to develop service user and carer research, and using research designs which actively include service users’ preferences. Meanwhile conceptual and methodological work to extend current approaches to multi-methods research is needed.11 At the same time, the recent development of the Mental Health Research Network in England will allow better effectiveness trials in mental health, both for studies of individual treatments and of service level evaluations in real world clinical settings.12

Graham Thornicroft
Professor of Health Services Research
King’s College London, London SE5 8AF, UK

References

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